



The Arc[®]

Tennessee

CONSERVATORSHIP and ALTERNATIVES TO CONSERVATORSHIP



***A guide for individuals with disabilities and
their families***

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Purpose

The Arc Tennessee empowers people with intellectual and developmental disabilities (I/DD*) and their families to actively participate in the community throughout their lifetime. People with I/DD sometimes need assistance in decision-making and protection from potential harm even in adulthood. Families and others involved in the lives of people with disabilities need accurate information to provide that assistance while preserving individuals' rights to the greatest extent appropriate.



There are a variety of ways to provide assistance to an adult with I/DD, including, but not limited to, *representative payee, durable power of attorney, supported decision making, health care surrogate, conservatorship and others*. However, little “family-friendly” information has been available about all the options, the processes and the costs to each one. The Advocacy and Education Committee of The Arc Tennessee developed this booklet to help answer questions about alternatives to conservatorship and conservatorship in Tennessee.

This booklet is not intended to provide legal advice, or to substitute for consultation with an experienced attorney. Each individual and family has unique circumstances. Laws and resources may change from time to time. Other agencies or attorneys may have differing views of Tennessee laws and regulations. *Advice from an attorney should be sought for answers to specific questions.*

Our goal is to provide accurate, useful information to assist families and individuals in making wise choices about their particular situation.

A sister's view: Arriving at the conclusion that conservatorship is needed for a family member is an emotional rollercoaster ride; mixing love, sadness, anger, confusion, guilt, caution, anxiety and hopefulness. The journey requires patience, information, and knowledge of the Medicare and Medicaid systems, a lawyer well versed in the development of conservatorship documents and the court system, and a thorough belief that this step is in the best interest of the person with the disability. The reasons for seeking conservatorship are as diverse as families themselves. The relationship between the conservator and the person does not need to change even though the person becomes a ward of the court. If decisions were talked about and made jointly prior to the appointment as a conservator, this arrangement should not be different afterwards.

* “Intellectual disability” has replaced the outdated phrase “mental retardation”

Introduction

Many people with **I/DD** can manage their own affairs with informal help and guidance from family and friends, not unlike the rest of the population. This booklet offers suggestions on how families and other support persons can structure that more informal assistance and guidance and what is involved when more restrictive protections are needed. It explains a variety of approaches to protecting vulnerable Tennesseans, including **conservatorship**.

The pros and cons of seeking conservatorship must be carefully considered. The appointment of a conservator is a serious matter because it limits a person's independence and rights. Conservatorship is *not* mandatory for a person with I/DD. It should *not* be done for the convenience of providers or other entities. However, in some situations, establishing conservatorship is the best way to protect a vulnerable individual. There is no magic formula to determine when or whether conservatorship is appropriate. An individual's abilities, needs and rights must be the strongest consideration in deciding to seek conservatorship.

There are strongly differing opinions and perspectives on conservatorship within the disability community and beyond. You will note several sections where we indicate that there is disagreement within the legal community about a particular practice or an aspect of the process. Some people believe that decision-making for an adult with an intellectual disability should always be overseen by the court, to keep the person safe and to protect her/him from conflicting interests. Others focus on the preservation of rights, self-determination and informal, natural supports.

Competence and *capacity* are legal terms used in determining the need for a conservatorship. They are complex, emotionally charged ideas. The intent of this booklet is to present an array of options for families to consider and evaluate. Some strategies will fit your family; others may be entirely inappropriate. Given the diversity of family circumstances and the uniqueness of each person, no single plan can be right for everyone.

Thinking about an individual's competence and ability to make decisions can bring up many tough emotions. Families may feel torn between concerns about safety and the desire to promote independence. Emotions such as anger, guilt or sorrow may reappear. Families whose adult children have developmental or intellectual disabilities often face hard choices.

Please know that all of these feelings are natural and "normal." You are not alone in experiencing them. Talking with other families can be both comforting and helpful. Your chapter of The Arc can be a resource to you, and help you connect with other families and professionals as you make important decisions.

It's never easy to plan for the time when you'll be gone, and all the more so when a family member has disabilities. Make an opportunity for family conversations now, so that you can think through your plans together before the family is faced with a crisis. *Whatever choice(s) you make, be certain to share copies of any relevant documents with everyone involved in the day-to-day support of the individual.*

For ease of discussion, this booklet makes references to parents, sons and daughters. However, we know that other family members—siblings, grandparents, aunts and uncles—are often deeply involved in the life of an individual with disabilities, and face the same questions and issues which this booklet addresses.

Again, the goal of this booklet is to equip you with accurate, usable information about conservatorship and alternatives to conservatorship in Tennessee, so that you can make the decisions that are best for your family. Words which are in **bold and underlined** are defined in the glossary at the back of the booklet.

The Advocacy and Education Committee, The Arc TN

One family's view:

Our son S. is 25 years old and does not have a conservator. He chose his career path at age 12, so we structured our family finances to support his work ethic and desire to be a wage-earning, tax-paying (and voting!) citizen.

Nine years ago, he opened his "truck account," saving up for a vehicle for his lawn-care business, to replace an archaic & notoriously unreliable '80 Ford Econoline van with non-functioning headlights, windshield wipers, horn, heater as well as an unwillingness to go uphill. Last month, he bought a big honkin' brand new pick-up truck, signed the contract and paid cash on the barrelhead.

Without our involvement, could an unscrupulous salesperson have taken advantage of him? Probably. Did we agree when he decided he was done with school and signed an IEP exiting special education? Nope. Does he daily make less than stellar choices about food and personal care? Absolutely, like everybody else we know. During a recent ER visit, was I worried that the physician might decide that he was unable to give informed consent? Yes, to the point of gnawing off my fingernails.

But observing his due diligence as he checked out photographs of truck options (and I can promise you, he was utterly immune to his mother's influence)—and his beaming pride as he gives everyone who enters our zip code a guided tour of his truck, affirm our belief that he and other people with developmental or intellectual disabilities must have the right to make important decisions, even unwise or weird decisions, unless there is clear risk of substantial harm. Our family will still consider/discuss/weigh/agonize/argue over the complex intersection of protection and self-determination, of freedom and safety. So far, so good. The adventure continues.

Overview of Guardianship and Conservatorship

Minor Children - Guardianship

By law, all parents have decision-making power over their own **minor** children. In Tennessee, the term **guardianship** is used to describe the legal relationship between minor children and their parents. The law does not distinguish between children with intellectual or developmental disabilities and those without a disability. All children up to the age of eighteen are under their parents' guardianship.



If one parent dies, the surviving parent continues as natural guardian. If both parents die before the child reaches legal adulthood, the court appoints a guardian to act in the place of the parents. The court appointed guardian will remain in this role until a court removes the guardianship or the child reaches the **age of majority**, whichever comes first.

It is particularly important for families of children with disabilities to document in your will the individual(s) whom you would want to care for your son or daughter in the event of your death. A court will usually respect the parents' wishes, although it is not required to do so.



Adults - Conservatorship

All adults are legally considered to be competent and to have the ability, or **capacity**, and right to make decisions about their lives. When people with intellectual or developmental disabilities become adults, they have all the legal rights and responsibilities of adulthood.

Conservatorship is a court-approved and court supervised legal relationship between a **competent** adult (known as a conservator in TN; as a guardian in other states) and an adult who needs assistance in decision-making. The person who needs assistance is referred to as a **ward** in legal documents (in this booklet, referred to as the "person" or the "individual"). The court gives the conservator specific authority and duty to act on behalf of the individual in making specified types of decisions affecting the person's life, but the court maintains authority.

Each state has a set of laws on conservatorship. There is no uniform national conservatorship law.

In Tennessee, the definition of a conservator is *a person appointed by the court to provide partial or full supervision, protection and assistance*. The court has the final decision-making responsibility and authority in those areas, such as health care, living arrangements and/or finances, for which conservatorship has been deemed necessary. A conservator acts as the agent of the court. All rights stay with the individual except for the specific area(s) in which the court transfers decision-making to the conservator.

Conservatorship is a legal, not medical determination. Only the court can make one person the conservator of another person. The court's decision is based on the determination that a person lacks **capacity** (or legal ability) to handle specific personal decisions, money and similar matters. The court will review reports from doctors, psychologists, or others with relevant information, but only the court can assign legal conservatorship over a person, although a physician's or psychologist's statement is required to establish incapacity. A petition for conservatorship should not be filed simply because an individual has turned 18, or for the convenience of providers or other professionals.

A court's order for conservatorship should be very specific as to which **rights** are removed from an individual. Conservatorship can and should be set up to preserve as many rights to decision-making as is appropriate for the individual. In some situations, less intrusive alternatives, such as a joint bank account or **power of attorney** can provide some or all of the protections an individual needs. In making decisions about conservatorship, it is important to think about the individual's specific abilities, needs, support network, and situation. Some individuals with severe intellectual disabilities are not able to make decisions about important matters. The level of disability and specific situations may narrow the options that would be appropriate.

Any adult has the right to make "bad" decisions, decisions that aren't in his/her best interest or that are contrary to advice (such as eating junk food instead of a healthy meal, spending extra money rather than saving it). *Eccentric or unusual choices are not grounds for conservatorship.* However, if a person consistently makes significant, harmful decisions and does not seem to understand the consequences, conservatorship should be considered. (Also see the section on **reasonable person standard**.)

A family discussion can help assess an individual's decision-making capacity. As appropriate to the particular circumstances, the individual should be involved in such conversations whenever and by whatever means possible. The discussion should include how much, if any, assistance the individual needs to:

- seek medical care when s/he is sick or injured
- understand the need for medical treatment that might be painful or unpleasant
- make medical appointments
- make financial decisions
- pay bills or taxes on time
- understand the consequences of signing a contract
- manage a checking or savings account
- handle a paycheck or benefits check
- understand the value of money
- comprehend the idea of personal safety
- make sound decisions about living arrangements and personal care
- understand letters/notices, such as from a physician or a landlord

From a self-advocate with autism:

I have lost thousands of dollars to money mismanagement. The abstraction in prioritizing expenses and the abstraction of money tasks negatively impacted my ability to master money management. "Float" and checking account fees confused me. Simple math tasks were not simple for me. I was in my late 40s before I came up with a strategy.

I was unable to make good choices and decisions and I needed someone to keep me safe. I needed help. I needed help making choices, understanding consequences, identifying safe people from those who could result in bruises that would take a lifetime to heal...mentoring and a guardianship relationship could have saved me much pain and in turn, may have helped me reach my true potential.

Alternatives to Conservatorship

If there are questions about a person's capacity to make decisions, less restrictive ways to provide assistance may be available as alternatives to a conservatorship. It is helpful to identify the specific situation(s) prompting the consideration of conservatorship. In weighing whether an individual is competent to make decisions in a particular area, consider:

- the complexity of the decision
- whether the decision would be consistent with the way the person has been living her/his life
- the consequences and risks involved in the decision
- whether the person would know how to get assistance to make a decision, if needed

Then, think about solutions to the situation that are less intrusive first, remembering that more restrictive options are appropriate in some circumstances.

For example, someone who has trouble managing money may not need a legal conservator. The person may only need a restricted or joint bank account and the support of a case manager, family member, or **representative payee** for help in budgeting money and paying bills.

Sometimes people with intellectual disabilities may simply need more or different information about a decision, such as a social story or video instruction. If a family member or friend can provide additional information, or persuade the person to voluntarily make an important decision, the need to file for conservatorship might be eliminated. However, care should be taken to not override the person's wishes, or use undue influence in assisting decision-making.

Below are some strategies that can provide protections or supports. It is a good idea to consult with an attorney experienced in disability issues to make sure that government benefits aren't jeopardized or other legal problems created.

Please note that not everyone believes that viable "alternatives" to conservatorship exist. From this perspective, if a person has the capacity to make decisions and understand the consequences of those decisions, the measures described below would interfere with that person's **autonomy** or right to self-determination. If, on the other hand, the person cannot make sound decisions, these strategies might allow another individual to have undue influence or to substitute his/her judgment without being appointed by a court to do so.

Another point of view suggests the concept of **supported decision making**: that individuals with intellectual disabilities can make decisions with support, advice and assistance from trusted people involved in their lives. With this approach, however, it's essential to ensure that the individual's choices and preferences drive decision-making, not the wishes of even the best-intentioned supporter.

Representative Payee

Some individuals with disabilities receive government, military or other benefit checks. Many individuals can manage these checks. However, others may not understand money management or are vulnerable to exploitation.

The administrator of these benefits, such as the Social Security Administration (SSA), may assign a **representative payee**. The payee receives the check and must use the money to benefit the individual. In some cases, family members serve as representative payees. Organizations (i.e., community mental health centers or Medicaid Waiver providers) also can serve as representative payees. The payee must account for the use of the benefit check, and is liable to repay money if it is mismanaged.

The decision to assign a representative payee is usually based on non-legal documents such as a doctor's report. The process for assigning a representative payee is relatively simple, and does not have the court costs associated with setting up a conservatorship. Contact your local SSA office or the administration office for other benefits for more information. You may also find helpful information on SSA's web site: <http://www.ssa.gov/payee/>.

Joint Property Ownership

Families often worry about their son or daughter's skills in managing their own home. They may fear the property won't be cared for, lost due to unpaid taxes or sold against their wishes.

In some situations, these scenarios may be avoided by placing property in joint ownership under the names of the individual with disabilities and another trusted person. Joint ownership should be approached with caution. Unless the third party has actually contributed to the purchase of the property, there may be gift tax and income tax consequences. Property worth more than a certain value, if not connected to the person's home, may jeopardize a person's SSI benefits.

Joint ownership may create other problems. For example, if a sibling who co-owns the property were to divorce, the sibling's spouse could claim a portion of the property under a community property settlement. The jointly owned property could also be subject to creditors if the co-owner were to have financial problems. Also, if the individual is found to lack capacity by a court at a later time, the property could not be sold without approval from the court.

Joint Bank Account

Most banks can assist with setting up bank accounts to help manage money. For example, benefit checks can be directly deposited and some bills automatically paid. It may also be possible for spending money to be sent regularly to the individual from his/her account. A joint bank account can help an individual manage money and prevent overspending. [WARNING: They can take all the money.]



Special Needs Trust

A **Special Needs Trust** can protect money or other property from being mismanaged, and enable an individual to stay financially eligible for benefits. A special needs trust is a legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual with a disability. The trust protects an individual's assets without requiring that s/he be declared incompetent by a court. A trust may also make it possible for the individual to receive extra income without losing state and federal benefits.



The primary consideration in your family's financial planning is to ensure that gifts, assets and inheritances, including payouts from life insurance, are not given or willed directly to the individual. A special needs trust will allow the individual to remain eligible for benefits as well as protecting the assets from misuse.

*Special Needs Trusts should be set up with the help of an attorney experienced in wills and special needs trusts and familiar with the law relating to government disability benefits. If the trust is set up incorrectly, the person might be disqualified for SSI, Medicaid, and other important benefits. A carefully written, **irrevocable** trust may eliminate the need for conservatorship.*

Living Will/Healthcare Directive

A **living will** or **healthcare directive** spells out what medical treatment a competent individual wishes or does not wish to receive when the person is unable to communicate that information. A doctor who receives a properly signed and witnessed document is supposed to honor the instructions or transfer the patient to a doctor who will.

Durable Power of Attorney

A **durable power of attorney** (DPOA) is a legal document that gives someone authority to make decisions on behalf of another individual. DPOA may be given for healthcare or financial decision-making. A DPOA for educational decision-making can be established once a student turns 18, if the student needs and wants assistance in making decisions about his/her Individualized Education Program (otherwise, the right to sign the IEP transfers to the student).

The DPOA must be in writing and notarized. In order for the DPOA to be valid, ***the individual must be considered competent at the time s/he signs the document.*** People with significant intellectual disabilities may not understand the idea of a DPOA and so are unlikely to be considered competent. The attorney should document the involvement of the individual with a disability in the decision-making process. The person must be able to indicate clearly that s/he wants a certain individual to make decisions on her/his behalf.

Only competent adults can consent to give or receive a DPOA. In order to sell real estate property, or to be accepted by most financial institutions, the DPOA must be notarized so that it can be recorded with the Registrar of Deeds. The document goes into effect once it is signed and can be ended at any time by either of the parties. A durable DPOA stays valid even if the individual's capacity to make decisions changes.

There are benefits and drawbacks to this option. Benefits are that the individual remains competent in the eyes of the law; the person who holds the DPOA can assist and act on behalf of the individual; and the court is not involved in the individual's life.

A drawback is that since the individual remains competent, s/he can enter contracts or make decisions that could cause substantial harm. If this possibility is a concern, the person may in fact lack capacity, and more intensive protections would be needed. Third parties, such as health care providers or bankers, are sometimes unwilling to recognize a DPOA. Particularly if the DPOA is several years old, you may need to get a statement from the attorney that it continues to be in effect.

DPOAs are **revocable**. The individual on whose behalf the DPOA was created can withdraw it at any point and without giving notice. If this happens, you must notify all the third parties with whom you did business to let them know that you are no longer authorized to act on an individual's behalf.

Someone with a DPOA can, on behalf of an individual, as authorized by the terms of the DPOA:

- endorse and deposit checks payable to the person
- open a bank account
- sign a lease
- admit the person to a hospital
- agree to or refuse health care
- buy or sell property
- file tax returns

It's important to keep both a living will and DPOA readily available. If you have an e-mail account which allows access to your e-mail from other computers (web-based), you can e-mail these documents to yourself to keep on file. It's a good idea to also send a copy to another family member or trusted individual as a backup. This information can be saved to a USB memory drive (also known as a flash or thumb drive), labeled as "emergency medical information" and attached to a keychain.

The TN Health Care Decisions Act Informed Consent

Informed consent is the permission given by a person before a medical procedure, treatment or certain other activities (such as participating in a research study). In order to give informed consent, the individual must understand possible risks, benefit and side effects, and legally agree to accept the risks in writing.

Informed consent has three basic components. In order to give informed consent, a person must:

- know what the choices are,
- understand the consequences, risks and benefits of the choice,
- make the choice that a **reasonable person** would make.

The first element is clear and relatively easy to determine. It may be harder to assess whether a person with ID fully understands all the possible consequences of an act or decision. Many people *without* a disability have a tough time working through every potential consequence of a complex decision.

Reasonable Person Standard

The idea of a "reasonable person" is even trickier to analyze. What is reasonable to a person of a certain age, culture or background might seem extremely unreasonable to another adult in different circumstances. However, one constant in figuring out this standard is that a choice to engage in an illegal act will be considered unreasonable in the eyes of the court and the legal system.

Defined from a legal perspective, a "reasonable person" is *a person who exercises qualities of attention, knowledge and intelligence, and the judgment that society requires of its members for the protection of their own interest and the interests of others.*

If the person satisfies the first two requirements above, knowing the choices and understanding the consequences of a decision AND the choice does not break a law AND doesn't pose an immediate, grave danger, a court is likely to find the decision to be reasonable.

Health Care Surrogate



In some situations, a person cannot give informed consent, because of an inability to communicate, unconsciousness or because s/he doesn't fully understand the treatment. For these cases, if no other person has already been given legal authority to make health care decisions, the Tennessee Health Care Decisions Act, (T.C.A. Section 68-11-170), provides a process where the treating physician can designate a **surrogate**. This scenario typically applies to people who are temporarily incapacitated and need medical care.

In some ways, the Tennessee Health Care Decisions Act is similar to the provisions of a durable power of attorney. However, it does not require a specific written warning; and the ways to revoke it are more limited (in writing or personally informing the supervising health care provider) than revocation of a DPOA (can be done at any time and in any manner that communicates an intent to revoke). Unlike with the assignment of a DPOA, though, the physician, not the individual, decides whether a surrogate is needed and who will take on that role.

This act covers all persons, with or without disabilities. However, there is disagreement in the legal community as to how the act applies to people with intellectual and/or developmental disabilities.

The Health Care Decisions Act (HCDA) states that it does not *authorize a surrogate to give consent for, or take any action on behalf of, a patient on any matter governed by Title 33*. Title 33 is the part of Tennessee's law that deals with mental health and developmental disabilities. It is somewhat unclear whether this language refers to anyone with an intellectual or developmental disability, OR only to those people receiving services through the Department of Intellectual and Developmental Disabilities (DIDD).

Title 33 does talk about *routine* healthcare decision-making. The section below (33-3-218) refers specifically to *service recipients*, which means *a person who is receiving service, has applied for service, or for whom someone has applied for or proposed service because the person has mental illness, serious emotional disturbance, or a developmental disability.*

According to this part of the law, if a service recipient:

- related to a developmental disability, is unable to make an informed decision about a routine medical, dental or mental health treatment
- AND the incapacity is shown by the fact that the person is not able to understand the proposed procedure, its risks and benefits, or the available alternative procedures

THEN the person *lacks capacity* to make a decision about that matter at that point in time. In this situation, a health-care provider would refuse to accept the person's consent and might ask that a court appoint a conservator for health-care decisions.

Because this section of Title 33 refers to "routine" medical decisions, most likely the TN Health Care Decisions Act applies to people receiving services from DIDD and who do not have a conservator, ONLY in emergency situations.

However, another part of Title 33, (33-3-219), addresses surrogate decision-making on routine healthcare issues and allows it in the following situations:

- When an adult with developmental disability that is not based solely on a diagnosis of mental illness or serious emotional disturbance does not have a conservator;
- AND a licensed dentist, psychologist or physician determines that the person lacks capacity to make a decision about routine medical or mental health treatment, AND
- someone is eligible to serve as a surrogate decision maker, AND
- the individual does not reject that person.

Under those circumstances, the process of surrogate decision-making is very similar to what the HCDA allows. The surrogate should:

- know about the person's disability and condition,
- be actively involved in the person's life,
- be willing and able to make the decision,
- make the decision in the person's interest,
- have no conflict of interest with the person.

Preference for the selection of the surrogate is given in the following order:

- The person's spouse
- The person's adult child
- The person's parent or stepparent

- The person's adult sibling
- Any other adult relative
- Any other adult.

Supported Decision Making

Supported Decision Making (SDM) is a tool that allows people with intellectual and developmental disabilities to retain their decision-making rights by choosing trusted supporters to help them make choices. It is a less restrictive alternative to conservatorship because it preserves the rights of the person with a disability to be the ultimate decision maker in decisions that impact his/her life. A person using SDM selects trusted advisors such as family members, friends, or professionals to serve as supporters. These supporters provide the person with a disability the tools to make their own informed decisions by agreeing to help the person with a disability understand and consider their options, and if necessary, communicate the decisions to a third party. In many situations SDM will be an informal process. In other situations, SDM may be operationalized through a more formal agreement, such as a Durable Power of Attorney (DPOA) or other document, that outlines how the supporter helps the person make decisions, what decisions the supporter helps the person make and under what circumstances the decision-making authority may get transferred to the supporter.

SDM looks different for everyone. It means finding tools and supports to help a person with a disability understand, make, and communicate his or her own choices. Examples of these tools might be:

- ✓ plain language materials or information in visual or audio form
- ✓ extra time to discuss choices
- ✓ creating lists of pros and cons
- ✓ role-playing activities to help the person understand choices
- ✓ bringing a supporter into important appointments to take notes and help the person remember and discuss her options

To learn more about SDM, visit the National Resource Center for Supported Decision Making at <http://www.supporteddecisionmaking.org/>.

A self-advocate's view:

I am a self-advocate with Cerebral Palsy. I think [conservatorship] should be the last resort for people with developmental disabilities. There are many alternatives to this. In my case I got a friend on my bank account to be my legs and hands for my money issues. She also gives me advice when I need it and I got two medical power of attorneys if I need help with that. The state is trying to take so many of our rights away we should not give them away. If a person needs a [conservator] make sure the guardian cares about the person and isn't in it just for money.

Conservatorship

Reasons for Conservatorship

An individual with intellectual or developmental disabilities may need a conservator if:

- s/he does not understand how to manage finances.
- s/he needs medical care or other services that will not be provided unless there is a clear understanding about the person's legal capacity to consent. Health and service providers are increasingly concerned about liability when providing services to someone who may lack the capacity to give informed consent.
- s/he has turned 18 and is still receiving special education services, but is unable to make her/his own decisions. All rights for educational decision-making, including signing the IEP, transfer to the student at age 18, unless conservatorship or DPOA has been established.
- parents or siblings cannot access important records, make appointments or provide information to health care or service providers. Health and service providers may require documentation of the person's legal standing before allowing families to access records. The federal law, the Health Insurance Portability and Accountability Act, or HIPAA, prohibits health care providers from releasing health information or records, such as medical history or insurance claims, without consent from the patient or client.
- s/he is making decisions which greatly endanger him/herself or others.

If a family decides that their son or daughter requires the protections of conservatorship, the family should carefully consider the needs AND abilities of the individual. The person may be unable to manage her/his money, but is able to make decisions about other aspects of life, such as where to live. It is possible— and preferable—to set up conservatorship to address only the areas where an individual needs support, while protecting other rights.

Rights of the Individual

People with intellectual or developmental disabilities have the same legal rights as any other adult, except for those rights that have *specifically* been removed through the conservatorship process. Those rights include, but are not limited to:

- The right to give, withhold, or withdraw consent and make other informed decisions relative to medical and mental examination and treatment
- The right to make end of life decisions:
 - To consent, withhold, or withdraw consent for the entry of a "do not resuscitate" order or the application of any heroic measures or medical procedures intended solely to sustain life and other medications; and
 - To consent or withhold consent concerning the withholding or withdrawal of artificially provided food, water or other nourishment or fluids;
- The right to consent to admission to hospitalization, and to be discharged or

transferred to a residential setting, group home, or other facility for additional care and treatment

- The right to consent to participate in activities and therapies which are reasonable and necessary for the habilitation of the respondent
- The right to consent or withhold consent to any residential or custodial placement
- The power to give, receive, release or authorized disclosures of confidential information
- The right to apply for benefits, public and private, for which the person with I/DD may be eligible
- The right to dispose of personal property and real property subject to statutory and judicial constraints
- The right to determine whether or not the respondent may utilize a Tennessee driver license for the purpose of driving
- The right to make purchases
- The right to enter into contractual relationships
- The right to execute instruments of legal significance
- The right to pay the respondent's bills and protect and invest the respondent's income and assets
- The right to prosecute and defend lawsuits
- The right to execute, on behalf of the respondent, any and all documents to carry out the authority vested above
- Give or refuse consent to medical examinations and treatment
- Hold a valid driver's license after passing required tests
- Have relationships
- Marry
- Make choices about reproductive health

A carefully structured **limited conservatorship** allows a person to keep as much control as possible and reasonable over her/his own life. The conservator has authority only in specific areas where the person is not capable of decision-making. All other rights remain with the individual. In all circumstances, including when conservatorship has been established, the individual has the right:

- to be treated with dignity and respect
- to privacy and confidentiality
- to exercise control over any aspect of life which the court hasn't delegated to a conservator
- to have the conservator consider her/his wishes, preferences and opinions
- to safe and humane living conditions in the least restrictive environment that meets her/his needs
- to equal treatment under the law
- to ask the court to change, review or remove conservatorship

Whenever possible, the conservator should consult with the individual to understand her/his views and wishes. The conservator should learn as much as possible about the lifestyle, values and preferences of the individual. Taking all those factors into account, the conservator should make decisions that would, as closely as possible, reflect the wishes of the individual. This approach is called the principle of “substituted judgment,” and is considered to be the most respectful of the individual’s autonomy.

When it is not possible to learn the individual’s wishes, the conservator should talk with friends, family members, self-advocates, staff and others in the community with whom the individual has frequent contact. In this case, the conservator should make decisions based on the idea of “best interests”: what a reasonable person would choose after thinking about all the pros and cons of a particular decision.

Types of Conservatorships

Conservatorship is sometimes described as *conservator of the person* or *conservator of property/the estate/finance*. In conservatorship of the person, the individual needs a conservator to decide personal issues. These decisions may include where to live, consent for medical treatment, work, travel and other areas.

The court will identify specific decision-making areas under conservatorship of the person. The court may require periodic reports from the conservator about the conservator’s actions over the course of the year or other period.

A conservator of the estate/property usually has power over the individual’s finances, including income or assets, not the individual’s personal matters. The conservatorship is based on the person’s inability to manage assets or property. If a property conservatorship is established, the individual may not be able to endorse checks or have a bank account or credit card.

The court requires this type of conservator to protect the person’s property and use it for the person’s care, support, and general welfare. The conservator of the estate must keep good records and account periodically to the court. There may be additional cost for filing fees and for a court-appointed attorney to review the accounts. Tennessee requires a conservator of finances/property to put up a bond, although this requirement can be waived by the court.

Individuals receiving SSI and/or Medicaid Waiver services are allowed to have very minimal resources, limited to \$2000. If a person has no more than \$2000 in savings or other assets, the restrictiveness and reporting requirements for conservatorship of finances may outweigh the advantages. If a person has more resources, a Special Needs Trust or **ABLE Account** should be considered.

Most conservatorships in Tennessee are “limited” and all rights not specifically stated in the court order remain with the individual.

Conservatorships of a person with an intellectual disability should remove only those rights where the individual lacks decision-making ability. This is the “least restrictive alternative” required in the law.

In Tennessee, the codes have a standard that the protected person's rights are to be removed to the minimum degree necessary to protect him or her. Full conservatorship involves controlling every aspect of the person's life. Full conservatorship may be appropriate when an individual is not capable of making any decisions about her/his life.

Some states allow *temporary or emergency conservatorship*. Sometimes an emergency exists when a person needs immediate assistance with decision making, such as a medical decision or a situation of possible exploitation of that individual. This is very rare, especially for individuals with I/DD, and usually expensive, so this should be considered only in true emergencies.

The court can appoint a **fiduciary** for a period of time, who will have the authority that the court deems necessary to assist and protect the individual. The court will give the fiduciary the legal authority to handle a specific situation. When the problem is resolved, the court will either end the fiduciary's role or appoint a permanent conservator, if necessary.

The term **standby or successor conservator** refers to the person who serves as back-up to an appointed conservator and will step in at the court's direction, or when the current conservator can no longer serve in that role.

When a conservatorship is set up with two conservators, or **co-conservators**, (such as both parents), it is important to structure the order so that each co-conservator can act independently. If one parent is out of town, for example, it may not be feasible for both conservators to sign a document. Bank accounts function in a similar fashion: when an account is set up as *Jane and John Doe*, both signatures are required for every action. If the names are listed as *Jane or John Doe*, each person can access the account individually.

A family's story:

A couple of years ago something unthinkable happened--a relative of my husband's died and treated S. (with autism and then 19 years old) just like everyone else in the family and left him a bit of money! After we picked our jaws up from the floor, we called an attorney and told him we needed to set up a special needs trust and conservatorship (which we had put off because of various issues). So that event propelled us forward--plus we were able to use some of S.'s own money to pay the legal costs of setting both up. It went very smoothly—S. is essentially non-verbal, and no one would dispute that he needs us to make decisions for him (but honoring his choices as best as we can determine them.)

The Process

When a petition for conservatorship has been filed, the individual has the right to request legal representation at all stages of the process and must be informed about the possibility and the process to contest the petition, and/or to have the conservatorship removed. The individual has the right to try to prove that s/he does not need a conservator, or to disagree with a particular person serving in that role.

Each state has its own legal procedures or processes in determining the need for conservatorship. In Tennessee, the following steps are involved:

1. A concerned individual, usually a parent or other family member, files a petition with the court that has jurisdiction over the person whose competency is in question. Each county has a designated court that handles conservatorships. However, it is not the same court in every county. The court must be in the county where the individual with a disability lives. The court will require a filing fee around \$200 - \$300.
2. The court may appoint a **guardian ad litem** for the case. A guardian ad litem is an attorney that acts as an agent of the court. S/he will investigate the facts of the conservatorship petition. A court may choose to waive this requirement. The fee for this attorney ranges from \$500 to \$1,500, and can be as high as \$10,000 if the conservatorship is contested. If the person wishes to contest the petition, an **attorney ad litem** is appointed for this purpose.
3. A court date will be set and a notice of the hearing will be served on the respondent and any person, institution or residential provider having care or custody of the respondent by the guardian ad litem or by mail. The notice of the hearing is also sent to the proposed ward's immediate family. Service by mail, sent to the last known address of such persons or institution, is sufficient. Some judges require the individual to physically appear at the hearing, but this condition is usually waived by the court. If the person's medical condition prevents a personal appearance in court, some judges will require a physician's letter explaining why s/he cannot appear in court. If the individual opposes the conservatorship petition, the court will probably require that s/he attend the hearing.
4. The judge bases the decision to appoint a conservator on evidence. The judge decides the amount and nature of the evidence. In all cases, there must be a psychologist's or psychological examiner's statement certifying that the person does not have capacity. Some judges may be willing to establish conservatorship based on the family's testimony. Others may require additional evidence from professionals, such as other physicians, psychologists or social workers but only if the matter is "contested".
5. After hearing all the evidence, the judge will rule on the person's competence, whether conservatorship is necessary, and if so, in which areas. The court assumes responsibility for the person in those areas where conservatorship is deemed appropriate. The court then appoints an agent of the court, or conservator. Usually the court will respect the family's wishes if a specific conservator is requested.

6. In some courts, the conservator will not have authority to act until the Clerk issues a Letter of Conservatorship that shows that the conservator has posted bond, if required, and sworn oath.
7. The conservator is responsible for reporting to the court. Each county court has different reporting requirements. It is the responsibility of the conservator to determine what the requirements are and to follow them. In some circumstances, the reporting requirements may be minimal. In others, detailed reports can be required.
8. If the judge determines that the conservator is not fulfilling his or her responsibilities satisfactorily, the judge may appoint a different conservator.
- 9. If a person who has a conservator moves to a different county, the conservatorship must be transferred to the court in that county.**
- 10. If a person who has a conservator in another state moves to Tennessee, a new petition for conservatorship must be filed in the county of the person's residence and all the steps followed to establish conservatorship in Tennessee; although this can be done by transferring the conservatorship under the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act.**

A family's story:

I became conservator for my 21-year old son, D., last fall. I recommend interested parties know more about the responsibilities and consequences BEFORE completing the process than I did. It may have frightened me away though, and I believe the move was necessary since my son cannot speak for himself. After my initial shock, I have come to terms with the reporting, which is minimal in his case because of the small resources. The case took over a year because the first lawyer stalled out. But the one who picked it up moved it on quickly.

Protecting Yourself

Being your son's or daughter's conservator does not mean you are personally responsible for her or his actions. Unpaid bills or damaged property are the individual's financial responsibility. You are not required to use your own assets to satisfy those debts. However, if you have conservatorship over property and finances, you must use those funds which are under your control to pay bills and make restitution.

When signing legal documents on your son's or daughter's behalf, such as a lease or a contract, you should make your status as conservator clear. You can do so by printing the individual's name and your name with your role:

Mary Smith, by her legal conservator, Jane Jones

Then, on the signature line, use the same format, which will clarify that you and your personal assets are not party to the contract.

Finding an Attorney

If the individual receives services through the Tennessee Department of Intellectual and Developmental Disabilities, DIDD may provide an attorney and may pay for setting up a conservatorship, although there is a waiting list for those services. If you meet the financial guidelines, your local Legal Aid Society may provide the necessary assistance if it fits within their established priorities.

If you plan to use a private attorney, it's important to find someone who has knowledge and experience with conservatorship and disability or elder law. Ask other families in your community, and contact your local chapter of The Arc or The Arc Tennessee for the names of experienced lawyers.



Successor Conservator

It is advisable to name a **successor** (sometimes called testamentary) conservator in your will. A successor conservator is the person whom you wish to become the conservator for your son or daughter after you die or can no longer fulfill the role of conservator. You can also name a standby conservator or co-conservators in the original order. Oftentimes, parents will name a sibling or two as standbys.

The person named as successor conservator should be carefully selected and should agree to this responsibility. You will want to consider someone who is likely to outlive the ward. However, a court will have to authorize this person before s/he can legally take this role.

A situation may arise where a conservator is unavailable to perform conservatorship duties. If the appointed conservator cannot perform the legal duties, then this person should resign and ask the court to appoint a substitute conservator. **In Tennessee, conservatorship can only be assigned by the court and is not transferable from one person to another.**

Because the designated conservator will have responsibility for making decisions about the person's living arrangements, health care and/or other matters, s/he should know the individual, and also should know where to look for advice and support. **The conservator should view her/himself as an advocate for the individual and should be able to respect and interpret the person's preferences and wishes.**

Consider making provisions to cover the successor conservator's out-of-pocket expenses for travel, professional consultation and other activities, from the individual's funds or from a trust. A conservator should have access to the advice of an attorney and the means to pay for that advice if necessary.

There are certain qualities and characteristics you should require in the person who will succeed you as conservator. While this is not a complete list, the person should:

- Live relatively close to the individual
- Have enough time to assist this person and carry out the legal responsibilities
- Be willing to learn about programs and services for people with intellectual or developmental disabilities
- Be able to adapt to changing circumstances
- Have good property management skills if s/he is conservator of the estate

Consider preparing a “letter of intent” describing the personality and preferences of your son or daughter, although it is important to recognize that both the individual and the circumstances will change. Ideally, you should feel confident in trusting the conservator to adjust to changing circumstances and not attempt to predetermine what decisions should be made. It is your son or daughter’s life, even if he or she will need ongoing guidance or supervision.

Conservatorship Standards

As a parent who becomes the conservator of an adult son or daughter with intellectual or developmental disabilities, your relationship with your adult child is not likely to change dramatically. Even though you may have new responsibilities as a conservator, such as record- keeping and reporting to the court, your daily role with your son or daughter probably will continue as it did before the conservatorship. However, the responsibilities of conservatorship are significant, and worth thoughtful discussion and consideration.

In the early 1990s, the National Guardianship Association (NGA), a group of professional conservators, advocates and others adopted a code of ethics and standards of practices. The NGA has established standards covering areas such as informed consent, confidentiality, conflict of interest and self-determination. While these standards are oriented towards professional conservators, they provide useful guidelines which your family may want to review. Key points include:

- respecting and protecting the person’s rights
- exercising “care and diligence” on the person’s behalf
- taking the person’s preferences and desires into account
- maximizing opportunities for independence and self-determination
- ensuring that the person lives and receives services in the least restrictive setting possible

You can read or download a copy of the NGA’s Standards of Practice from their web site at: www.guardianship.org/pdf/standards.pdf

Public and Corporate Conservatorship

Sometimes there is not a parent, other family member or friend to act as conservator. Family members or friends may be unwilling, unavailable or not qualified to take this role. For these and other reasons, Tennessee has appointed public conservators and allows corporate conservatorship programs.

In some Tennessee counties, local public conservators are appointed by the courts. Typically, these individuals deal with issues related to aging, and may have less experience with disability issues. Their caseload may limit the time and resources available to assist their wards. This type of conservatorship should be considered only if there are no other options, especially for those who have the financial resources to look elsewhere.

The state of Tennessee allows incorporated agencies to provide conservatorship and related services. In these agencies, the corporation is the conservator and assigns a staff person or volunteer to carry out the conservatorship responsibilities.

Parents can contract for corporate conservator services to begin after their death; if they can no longer fulfill the duties of conservatorship; or if they prefer for an agency to serve in this role. State agencies also contract with these organizations for conservatorship services. **Remember, though, that conservatorship is not transferable and that only a court can appoint an individual or agency as conservator.**

Before contracting with a corporate conservatorship agency, you should investigate the organization to be sure it is well managed, has stable funding and provides quality services.

Emergency Conservator

In extreme emergencies, there are times when an emergency conservator must be appointed to make immediate decisions for the ward to protect their best interests. These are very rare and usually involve an elderly person who needs an immediate medical decision or is at risk of exploitation.

In an emergency conservatorship, a petition is filed, with supporting documentation, and a hearing must be held within five days, where an emergency conservator is appointed. The person must receive notice within 48 hours of the appointment and the person must be given an "attorney ad litem" to represent them in the proceedings.

Appointment of an emergency guardian or conservator, with or without notice, is not a determination of the respondent's incapacity.

The court may remove an emergency guardian or conservator at any time. The court may appoint a guardian ad litem to investigate the circumstances. The emergency conservator's authority will expire after 60 days unless made permanent by the court in a separate hearing where the individual is represented by an attorney ad litem.

Removal of a Conservator

Unfortunately, sometimes a conservator does not act in the best interests of the individual with a disability, or fails to carry out the court's instructions. This is a very serious matter, and the decision to remove or change a conservator must be made by the court.

A petition to address this problem should be filed in the court which established the conservatorship, by the individual, the individual's attorney, a family member or any concerned party. The petition should state the reasons a review or change is being requested. The court will schedule a hearing in which all parties can present their evidence. It is advisable that the person bringing the petition have legal representation.

A court may also make changes to or eliminate a conservatorship if the individual has developed additional decision-making skills or has a support network which makes conservatorship no longer necessary.

A family's story:

Some 10 years after my own diagnosis [with autism], as the parent of an 18-year-old, when we faced the conservatorship decision, there was none to make. It was obvious. Looking at my life experiences...I knew that I needed to parent him differently than my mother, and I knew that part of that was protecting him from much of the pain and suffering I had endured. With enthusiasm I accepted the need for guardianship for him. This is not necessary for all, but for my son, right now, this is what's needed.

Don't get me wrong; I am a big believer in self-determination and the entitlement to failure, but then again, for our son, he needs more time. Developmentally, he is not ready to make all of his choices. But each day we work toward more and more of those goals.



Checklist



Considerations for Establishing Conservatorship

- What are the specific circumstances which have prompted consideration of conservatorship?
- Have less restrictive alternatives been explored?
- Does the person:
 - understand the value of money
 - understand the concept of personal safety
 - have the capacity to give informed consent, i.e.,
 - know what choices are possible
 - understand the risks, benefits and consequences of the choices
 - make the same decision that a reasonable person would make
 - need medical care or services which won't be provided unless there's proof of the person's legal capacity
 - live in an environment that is significantly unsafe

- make choices which cause significant harm to self or others, rather than simply being unconventional or contrary to advice
- have a significant vulnerability to exploitation
- What are the specific areas in which the person may lack capacity?
 - Living arrangements
 - Personal safety
 - Finances and property
 - Health care
 - Educational decision-making
- What rights could the person retain with a limited conservatorship?
- What rights would be removed from the person?

Steps to Establish Conservatorship

Remember that there is variation from county to county and from court to court in how the process is carried out. Some steps may be waived by some judges in some circumstances.

- A petition is filed in the court which has jurisdiction over the individual.
- A guardian ad litem may be appointed for the individual to ensure that her/his right to due process is protected.
- The individual may contest the petition.
- A physician's statement is submitted, documenting the person's lack of capacity.
- The guardian ad litem investigates the facts of the petition and reports to the court.
- The judge requests and considers additional evidence at her/his discretion.
- A hearing is scheduled.
- At the hearing, the judge rules on the person's competence, whether conservatorship is necessary, and if so, in which areas.
- The court assumes responsibility for the person in those areas where conservatorship is needed.
- The court appoints an agent of the court, or conservator.
- The court issues an order defining the areas over which the conservator will have authority.
- The individual retains all rights which are not specifically removed in the order.
- The conservator is responsible for reporting to the court, as the judge requires.
- If the judge determines that the conservator is not fulfilling his/her responsibilities, s/he may appoint a different conservator.
- If a person who has a conservator moves to a different county, the conservatorship must be transferred to the court in that county.
- The individual, or others on her/his behalf, can petition the court to remove or change the conservatorship order.

A family's story:

When C. was about 20 years old, he was called for jury duty. That was the first time we thought about him as a competent adult, and realized that he did not have the competence to serve on a jury or have the ability to understand the proceedings. With a note from his doctor, he was excused.

A few years later, a program manager at an agency showed us some papers C. had signed indicating that he understood that he had done something wrong. We knew he could not understand a paper with so many words. After all, he could barely read and he was happy to sign any paper put before him. This left him vulnerable to anything put before him.

We met with an attorney to discuss the options and decided that full conservatorship was appropriate. His inability to make complex decisions, especially about medical or financial issues was apparent. The guardian ad litem appointed to represent C. met with C. and his brother and sister. My husband I were appointed co-conservators by the court. After the death of my husband, C.'s brother was appointed co-conservator and his sister was designated as standby conservator.

I feel secure knowing that those who know and care about C. will always be able to represent his desires and help make meaningful decisions on his behalf.

In Conclusion

We hope that you have found the information in this booklet to be useful, thought-provoking and supportive. Determination of capacity, preservation of rights and protection from harm can be among the most challenging issues that individuals with intellectual or developmental disability and their families face.

We began this booklet with the idea of providing a brief overview of conservatorship; alternatives to conservatorship; and the steps to be followed in establishing conservatorship. The list of topics, as evidenced in the Table of Contents, expanded quickly. The subject matter did not lend itself well to generalities or broad, all-encompassing statements. We were also committed to presenting multiple perspectives, while staying grounded in the beliefs and values of The Arc.

The Arc Tennessee has a richly diverse constituency of self-advocates, families, professionals and others involved in the lives of Tennesseans with disabilities. Please help us in spreading the word about this booklet so that families will have the information they need to assist in decision-making. Additional resources are listed at the back of this booklet.

Glossary

ABLE Account—Achieving a Better Life Experience is a tax-free earnings savings program to help participants maintain independence and quality of life with little to no impact on federal means tested benefits <http://www.abletn.gov>

Age of Majority—the age when a person is considered an adult and has the responsibilities and rights of an adult. In Tennessee, the age of majority is 18.

Attorney ad litem—attorney appointed by the court to represent the individual who wishes to contest the conservatorship petition.

Autonomy—the right to make decisions; self-determination or self-direction.

Capacity—in this context, the ability to make informed decisions.

Competent—properly or sufficiently qualified, capable, or fit to perform an act.

Conservatorship—legal right given by the court to a person to manage the property, financial affairs, and/or well-being of a person found to be incapable of doing so.

Co-conservators—two conservators (such as both parents) who work jointly or independently to manage the affairs of another individual.

Developmental disability—a disability that begins between birth and age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. <http://www.nacdd.org>

Durable Power of Attorney—same as Power of Attorney except that it remains in effect even if the competency of the individual who gave it changes.

Guardian ad litem—an attorney who represents the individual who may need a conservator, ensures that the person's rights to due are protected and investigates the facts of the conservatorship petition.

Guardianship—in Tennessee, the legal relationship between children under the age of 18 and their parents; in some states, the same as conservatorship.

Healthcare Directive— (see **Living Will**)

Incapacity—lack of ability; in this context, inability to give informed consent.

Informed Consent—the process of obtaining a person's permission for a medical procedure or certain other types of activities, in which the person demonstrates knowledge and understanding of the choices; the risks, benefits, and consequences of the choice; and makes a choice that a *reasonable person* would make.

Intellectual disability—significant limitations in intellectual functioning and in social and adaptive behavior, in such areas as communication or daily living. ID begins before the age of 18 and can occur with or without other physical or mental conditions. <http://www.aaid.org/>

Irrevocable—cannot be withdrawn or cancelled.

Limited Conservatorship—legal right given to a person to manage only specific affairs of an individual with a disability, allowing the individual to maintain as much control as possible over his/her own life.

Living Will—a document that states what medical treatments an individual does or does not want to receive when the person is unable to communicate that information. *Also known as a healthcare directive*

Minor—a child who has not reached full legal age; in Tennessee, an individual younger than the age of 18.

Power of Attorney (POA)—legal document signed by a competent individual that gives another person authority to act on her/his behalf.

Reasonable Person—a fictional person who has and uses the qualities of attention, knowledge, intelligence and judgment that society requires for the protection of her/his own interests and those of others.

Representative Payee—a person appointed to manage Social Security or other benefit payments to an individual who needs assistance in managing finances.

Revocable—able to be reversed or withdrawn.

Rights—a justified claim or entitlement; personal liberties guaranteed by law.

Special Needs Trust—legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual with a disability without causing financial ineligibility for SSI and other benefit programs.

Standby Fiduciary—a person appointed by the court, usually on a temporary basis, who has the same duties and authority as a conservator. Sometimes used when an appointed conservator temporarily becomes unable to serve.

Successor—person appointed by the court to become conservator after the conservator dies or can no longer fulfill the role of conservator.

Supported Decision Making— a tool that allows people with disabilities to retain their decision-making capacity by choosing trusted supporters to help them make choices.

Surrogate—a person who acts in the place of another.

Ward—a person who is under the protection or in the custody of another individual or a court of law.

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